



Breaking Ground

Energy, Support, Positive Attitude— You Find Them All at Partners

By Coral Getino

When my friend Tracy told me about the Partners in Policymaking™ Leadership Institute (PIP) last year, and I applied, I didn't really know what I was getting into! I thought it would be much like the sit-and-listen training courses and conferences I have attended since my son entered Special Education.

For a few months, I didn't think about it much. Summer went by, and after my return from a month-long trip to my native Spain, I found among a hundred e-mails and phone messages the insistent calls from Ned Solomon, who couldn't figure out why I would not even reply. I had been accepted into the 2001-2002 PIP, and I had to commit by Friday!

PIP happens in Nashville, once a month for seven months, during Friday and Saturday, so I had to quickly assess what I would do with my students at the University of Tennessee and my sons until their daddy came home.

My son started school on the wrong foot. He had a brand new teacher and didn't react well to the change. He started having behavior problems, and he refused to stay in the regular classroom. The week of my son's seventh birthday the world we live in changed. The September 11 terrorist attacks brought fear into our home, as my husband works at Oak Ridge National Laboratory. I missed the first session of PIP, which was held the next weekend.

In October I traveled to Nashville a nervous wreck. I had never been away from my family overnight. I had never traveled more than 50 miles by myself. But I found the Doubletree Hotel on the first try. When I entered the room I felt like the new kid on the block; everyone already knew each other. But I shook it off. The first session was on independent living by the true experts: people with disabilities. I learned lesson no.1: *"Regard people with disabilities just like I regard others."*



Coral Getino and need
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Back to school. The next morning Mike Remus hit a nerve. He talked about inclusive education, and I bought into it. I couldn't wait to come home to share all that I learned with my husband and my son's Individualized Educational Plan (IEP) team. But things at school just got worse and worse.

Expectations from the school staff were so low that we went through 12 hours of developing an IEP. When it was time to talk about placement, we were worn out and just wanted to have it over with. My son would spend a minimum of 8.5 hours a week in first grade. We took the IEP home for a final review—and discovered that my son would be 35 hours in a self-contained class. I called another IEP meeting.

It was November, and PIP time again. This time I brought the IEP documents with me and discovered a true asset: my classmates. We had a spontaneous group meeting at the hotel lounge. Not only did they listen to my frustration, but they gave me tips and ideas.

When I came back home, I felt I could conquer the world. Another week went by without notice for an IEP meeting. By the time I got a meeting, just two days before the deadline, I had to attend by myself. Big mistake. I think I lost it when I heard that the impediment to further inclusion was my son's cognitive impairment.

When I got home I was ashamed and heartbroken. I touched bottom. Then I put in practice what I had just learned at PIP dinner entertainment: "Use comedy as escape!" I wrote a little skit on the quarrels of the founder of PPP (Pesky Persistent Parents) and a letter of apology that I faxed to the school. Two days later my husband and I came to a much nicer meeting arena. We got the IEP language amended; my son would be 25% included with a behavior plan, several hours of therapy, and the promise of meeting twice monthly in collaborative meetings to work out further concerns and inclusion.

The January PIP session brought to me a new self-awareness and acceptance of disability. I learned to think out of the box: when a door closes at school, another may open in the

community. Back home, I got an augmentative communication (AC) device on loan from the East Tennessee Technology Access Center (ETTAC). My son, who doesn't speak clearly, was to answer questions by pushing buttons. In ten minutes he could verbally state his com-

plete double last name, and made his maternal grandfather in Spain a happy man! We have discovered that visual and auditory stimuli help him learn!

Working together.

Partners from the last ten years attended the February PIP reunion and I have

never seen a more energetic crowd. Positive attitude is contagious. I started thinking about the BIG picture and how my individual actions could join others in a common cause. I participated in a grant application with ETTAC for Hispanic outreach, and I collaborated with Partners graduate Barbara Dyer in organizing a support meeting for Hispanic parents of children with disabilities.

March's session about government was very useful and practical—"When laws are not working, here is how we can change them"—but I truly enjoyed the passionate presentations of my all classmates. In retrospect, I see how much I have learned by practice—from legal language and summarizing information, to appreciating a podium when you have shaky hands!

Things at school have improved enormously. Communication lines are open, and my son is making a lot of progress. His negative behaviors are minimal. The school has agreed to use an AC device for instructional purposes, as well as to work to help my son improve conversational skills. He is also using an Intellikeys keyboard as an alternative to writing. He has progressed from spending five or ten minutes in homeroom to 90 minutes at a time. He participates in a reading group and journal time. His communication and social skills have improved enormously.

There is so much I still don't know! Through PIP I have gained new coping skills, a language and knowledge base, and a network of friends. I have renewed hope of a bright future for both my children, and confidence that I can help change the world—so can you! ■

Dedication:
To my PIP classmates,
they have helped me
discover the power
of a positive attitude.



Helping People Find Jobs That Fit

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By Jim Summerville



Helping people with disabilities to achieve their career aspirations—that's the purpose behind the Tennessee Customized Employment Partnership (TCEP). TCEP is a newly-formed partnership led by Workforce Connections, a division of the Knoxville-Knox County Community Action Committee.

TCEP estimates that some 26,000 people with disabilities live in Knoxville / Knox County. Some are served through job placement programs funded by two State agencies, Vocational Rehabilitation and the Division of Mental Retardation Services. Others are on waiting lists for such programs. But many individuals with disabilities don't participate in any sort of workforce development program.

TCEP will provide customized employment services to individuals who are either unemployed or underemployed, who are exiting education and seeking employment with support, or who are employed in segregated settings.

"Customized employment services stress person-centered planning," says Wendie Wilson, assistant director for Workforce Connections and project manager for TCEP. "We will help people coming to the Knoxville Area Career Center to make job choices that fit them, their abilities, their desires."

When they come to the Career Center, job seekers will receive individually designed job development, and staff will seek to place them in integrated employment settings (that is, not sheltered workshops). Successful job candidates will have support services and benefits management.

Other partners in TCEP bring various strengths to the project. UT-TIE (University of Tennessee Technology-Inclusion-Employment) has broad-based employer connections and well-established relationships to community rehabilitation providers and funding agencies. TransCen can call on national expertise in employment methodology. Services from the Disability Resource Center, which is Knoxville's Center for Independent Living, include independent living skills training. The East Tennessee Technology Access Center will contribute its expertise in workplace accommodation.

TCEP is part of a national initiative to incorporate workforce services for people with disabilities into "one-stop" centers. The Knoxville Area Career Center will serve as just such a "one stop" resource, connecting employment, education, and training services, says Ms. Wilson.

The planning stage of the project is now concluding. TCEP expects to begin delivering services by late spring. TCEP is funded by the Office of Disability Employment, a division of the U.S. Department of Labor. ■

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Jim Summerville

is editor of

Breaking Ground.

Project LINK—Making a Difference in the Lives of Kids with Different Abilities!

By Treva Maitland

Project LINK is a grant project awarded to The Arc of Tennessee by the Tennessee Council on Developmental Disabilities. LINK stands for Leaders In education Networking for Kids. Project LINK is a collaboration of The Arc of Tennessee with UT-TIE (University of Tennessee—Technology, Inclusion, Employment), STEP (Support and Training for Exceptional Parents, Inc.), and Tennessee Protection

and Advocacy.

Staff comprises three project specialists for education. Mary Ann Schenk works in the East region of the state, while Steve Jacobs works in Middle, and I work in the West. Our job is to organize the training programs in local communities for families and to facilitate these meetings. The training is directed to students with disabilities and families. LINK is also a wonderful networking opportunity for families to

meetings, but we could never fulfill the need with only three people working on the grant. Project LINK encourages families to advocate for one another at IEP meetings. One blessing of Project LINK is that every group has at least one participant who has supported other families at IEP meetings.

The young self-advocates who have participated in the training are the true treasures of the project. Imagine a third grade student, who happens to have cerebral palsy, being empowered enough to say "I would rather be called by my name instead of a label. I am Syler—not crippled." Imagine Blake, a 12th grade student who happens to have Tourette syndrome, dyslexia, and dyscalculia, being empowered enough to attend his own IEP meetings and to speak for himself.

Jessica Greer, who happens to have attention deficit hyperactivity disorder (ADHD) and dyslexia, knows first hand the rewards of Project LINK. She is a leader at Evangelical Christian School in Cordova where she receives a wonderful education alongside her friends and peers. In her classroom, you see more similarities than differences in the students. When other students need an advocate, they depend on Jessica.

There are many people with disabilities who attain fame. It's not that they overcame their disabilities. They learned to succeed with them because the disability is only a small part of who they are. Jessi is one of Tennessee's future leaders, thanks to her school, her family, her church, her community, the Learning Disability Association of Greater Memphis, and The Arc of Tennessee's Project LINK.

As part of LINK, Jessica has been participating in self-advocacy training with me. Self-advocacy means that people with disabilities speak or act on behalf of themselves or others. This action may be individual or it may be a group under-



Jessica Greer pictured with Senator Fred Thompson.

make the changes we so desperately seek in many public school systems in Tennessee.

Although LINK is diligently working to empower families to become effective leaders, there is a great need for individual advocacy in the area of special education. Our office receives many calls requesting a trained advocate to attend IEP (Individualized Education Plan)

taking; ideally, it's both. Self-advocacy often involves addressing institutional or public issues that affect people with disabilities.

Jessica zoomed through Project LINK's self-advocacy curriculum. She was like a sponge soaking up the Self-Advocacy manual, then moving on to *Seven Habits of Highly Effective Teens* by Sean Covey, son of Stephen Covey.

Self-advocacy training with Project LINK is only one of a multitude of opportunities that Jessica's parents, Pat and Tammy Mullins of Collierville, have given her. Jessica works in the office at school, and she takes part in swimming lessons, gymnastic lessons, CYAA.-soccer team and CYAA.-cheerleader, "Vols" participation, Happy Times Farm Day camp, CUMC. Puppet Ministry, St Mary's Overhill/Overnight Camp, St Mary's Counselor-in Training, CUMC. Basketball, golf lessons at Palmer Golf Course, Tennessee PGA Golf Academy, and a role in productions of "Helen Keller," "James & the Giant Peach," and other plays in drama club and Germantown Community Theatre. Through the University of Memphis, she has participated in "Kids in the Kitchen" cooking class, a manners and etiquette class, a "keyboarding" class, "Designing Your Own Web page" class, first aid and safety training, and chess class.

Jessica's family believes that we must all give back to the community. Accordingly, Jessica plans to volunteer as a coach for a youth leadership project this summer, sharing her knowledge and zeal with other students with disabilities. Jessica has done volunteer work with local Vacation Bible School, been a Volunteer at Baptist Memorial Hospital, and performed service work as a member of the Key Club at her school.

Where Jessica has a natural ability to lead others in positive directions, academic achievement is more difficult for her to attain. She receives books and magazines (including *Seventeen*) on tape from the Tennessee Library for Blind & Physically Handicapped because she reads differently than the typical student. She receives *In Focus*, a large print magazine free from the National Association for the



Jessica Greer pictured with Representative John Tanner.

Visually Handicapped, *The Student*, on disc free from Christian Record Services, *Teen Time*, in large print from the Lutheran Library for Blind, and "High School Spirit," on cassette free from the General Council of Assembly of God. She has participated in reading and math programs beyond what the typical student receives, and she is

privately tutored to give her the opportunities she needs to succeed in life.

In addition to Project LINK Self-Advocacy training, Jessica has had other wonderful recent opportunities. She participated in the Council on Developmental Disabilities Youth Leadership Forum at Vanderbilt University last year. As a guest speaker at The Arc of Tennessee's State Conference in Memphis, she excelled. Then, to top off the summer, she traveled to Washington, DC, where she met with Senator Bill Frist, Senator Fred Thompson, and Congressman John Tanner. While there, she participated in the National Self-Determination Coalition meeting during the Project Leadership National Leadership training.

Now, Jessica has set her sights on speaking up and speaking out for students with different abilities on a national level. There is no doubt that Jessi will reach her goal of national leader in advocacy, and we are proud to be a part of Jessi's team! ■

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Treva Maitland is West Tennessee regional project specialist for The Arc of Tennessee and a former member of the Tennessee Council on Developmental Disabilities.

Creating the Future— Involving Students in Developing IEPs

By Bev Adcock and Michael L. Remus

Individual Education Plans (IEPs) are how schools determine what services and supports students with disabilities will get. As the student gets older, they also include services to help the student get ready for adult life. An IEP is like a map that shows how the student will get to the future she wants.

IEPs can be a powerful tool for preparing students for adult life. It is important to include them in IEP planning because it is their lives that are being decided. Students can't decide the future if they don't get any choices about their lives right now. Students should help choose what they will need to know to live, learn, work, and play as adults. Students can also learn self-determination (making decisions about their own lives) by helping develop their Individual Education Plan.

Start involving students in IEP meetings when they are young. Even if the student can't stay for the entire meeting, she should be introduced. If test results are going to be discussed, some students might want to come after that part of the meeting is over. If students will be there to hear test results, prepare them ahead of time for what they will hear.

Students will feel more a part of the group if they have an assigned task. These can include making introductions, passing out refreshments, or handing out papers. As students get older, give them more to do each time. This helps students get used to IEP meetings. It also helps remind the IEP Team just whose life is being planned.

Before the IEP meeting

Students won't automatically know what an IEP meeting is or what to expect. Before the IEP meeting, assign a coach to the student to:

- Teach the student the reason for the meeting and who will be there
- Get him ready for IEP meetings

- Help the student decide which peers without disabilities to invite to the meeting
- Teach him rights and responsibilities
- Help practice saying what he wants
- Teach him how to make choices or decisions

Many students won't know how to make choices because someone else always chooses for them. Others may have voiced their opinions but were ignored. Some students will find it hard to say what they want in front of the IEP Team. Others may not know appropriate ways to express what they want. For these reasons, students may need some training in how to choose or say what they want.

An easy way to teach making choices is to do it with food. Students can be given two choices at first (chocolate or vanilla ice cream) and more options can be added later. This also creates the opportunity to teach what to do if their choice is ignored. If they ask for vanilla ice cream and get strawberry, what should they do? Some students may find they like the substitute better while others may hate strawberries. This can lead to a discussion of how to insist without being rude.

The student needs to know how to make decisions when she doesn't know enough. For example, if the IEP Team asks the student which elective classes she wishes to take, how does she decide? Sometimes we all have to make choices without having enough information. Most people get advice from friends or base it on things they do know—like what they like to do. Let the student know ahead of time about any decisions like this that she will be making at the meeting.

During the meeting

Work out some signals ahead of time so the student can ask for help if needed. Does the student know different ways to explain what he means?



Is there someone who can help explain if asked? There should be a friend or support person there to help the student if needed.

The student should:

- Be polite
- Ask questions if things aren't clear
- Know what he can do, needs to learn, and wants for the future
- Listen to what other Team members are saying
- Know what the IEP Team is deciding
- Say what kind of jobs he wants to try
- Say when things are not working

The discussion of transition goals is particularly important for students. Transition goals concentrate on what students need to know to live, learn, work, and play as adults living in the community. The IEP Team must start discussing transition goals by the time a student is 14.

Transition goals teach students skills that make life worth living. Many students with disabilities will need instruction in these areas. Without these skills, many adults with disabilities are lonely and don't have a social life or are dependent on others because they have never been taught to do things for themselves. When thinking about transition goals, the IEP Team and the student need to concentrate on the kinds of skills that will help the student to have a worthwhile life.

Living goals should teach students social skills, conversational skills, manners, and about making friends, dating, and marriage. It should also include independent living skills like personal hygiene, cooking, cleaning, meal planning, laundry, managing money, using public transportation, and grocery shopping.

Learning goals might include studying art, music, foreign languages, dance, or attending college or adult education classes. Attending college can be done for credit or just auditing classes in order to learn and meet people. It can also mean going to technical school to learn a trade.

Work goals should start by finding out what the student likes and can do. This can include interest inventories, volunteering at different jobs, job shadowing, on-the-job training at different sites, and job placement. Students can also learn how to keep track of the time they work, follow company rules, follow directions, and stay on schedule. More specific work skills can be identified once a student is in a job.

Students need to learn recreational and leisure skills also because play is an important part of most people's social lives. This can include learning different games and skills, planning and attending parties with friends, learning to dance, learning to buy tickets to events, and appropriate public behavior. Students can also learn to use community resources like the YMCA, theaters, concert halls, public library, movie theaters, and parks.

After the meeting

Talk with the student about what happened. Make sure she understands what was decided at the meeting. Let her know what she did right. Role play different ways to do things next time. Practice things that were hard to do so it will be easier next time.

Does this seem like a lot of work? Maybe, but students have a right to plan their own futures rather than having someone else make all the decisions for them. What better way to teach self-determination? ■

For more information, the authors may be contacted at

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This article was taken from a presentation by Michael L. Remus and Bev Adcock. Mike Remus is director of special education for Williamson County Schools. Bev Adcock has co-authored six books on special education and trained thousands of parents and teachers on the special education process. She is currently a behavior consultant for a countywide school district.

Partners Alumni Get Tune-Up at 8th Annual Reunion; 2001-02 Class Graduates

By Ned Andrew Solomon

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How are typically developing siblings affected by a brother or sister with a disability? How do individuals and families begin to understand and navigate TennCare and the insurance industry? How does one go about applying for a grant or creating a corporation out of a circle of support? When is the best time for a student to start participating in his own IEP meetings? And what is it really like to have visual and auditory challenges at the same time?

These thought-provoking questions were raised and answered at the Annual Partners in Policymaking Reunion at the Doubletree Hotel in Nashville this past February. Self-advocates and family members from across the State, representing the current class and eight previous classes, gathered to check in with old friends, make new contacts, pick up on the latest

developments in the disability field, and generally get reinvigorated about the Partners purpose.

Partners is a leadership training initiative of the Tennessee Council on Developmental Disabilities. The Institute is designed to provide adults with disabilities and parents of children with disabilities with the latest information on disability policy issues, and to help them become advocates for themselves and for others in their communities. The ultimate goal is to create a productive



(Above) Partners grad Carol Smith lighting up the lobby of the Doubletree Hotel. (Right) Another Partners grad Simon Fulford? Partners grad Andrea Cooper gives it her best shot.



partnership between people with disabilities and the people who make the policies that affect their lives.

Each year, a class of 25-30 participants is selected from across the State. Curriculum includes the State and federal legislative processes, assistive technology, building community, inclusive education,

personal futures planning, employment, history of disability, supported living and family supports. Sessions are conducted by experts in the disability field.

The Reunion is an opportunity for the program to depart

from the usual curriculum, and visit topic areas that are more time sensitive, or specifically requested by Partners in the current class, or from past classes' program evaluations. Another important component of the Reunion is the Regional Roundtables session, where Partners break into groups based on the State's three grand regions, and discuss issues of importance for families and communities in those areas.

This year, initiated by Ginny Cooke, a Partners director from the Phoenix Perth Institute in Chicago, Tennessee Partners established a special group with representatives from each of the graduated classes to research and respond to important legislative issues that impact the lives of Tennesseans with disabilities. The ultimate goal is to create a cohesive, unified statewide network of Partners who can collaborate with each other, and with individuals and organizations in their local areas to promote significant systems change.



Future aspirations? 2001-02 Partners grad Dr. Faisal Shamshad on the Capitol lawn.



Partners in Policymaking 2001-02 Class

Kathy Budai, Oak Ridge
 Anthony Chelena, Henderson
 Andrea Cooper, Nashville
 Christy Cox, Fairview
 Nancy Durant, Kingsport
 Wayne Dyer, Johnson City
 Coral Getino, Knoxville
 Susan Hiscutt, Kingsport

Julie Matejko, Madison
 Brian McHan, Jackson
 Mamie McKensie, Nashville
 Nancy Nolan, Nashville
 Mary Norville, Bells
 Amy Petulla, Chattanooga
 Sarah Philpott, Hixson
 Lynne Rucinski, Knoxville

Faisal Shamshad, Covington
 Jeffrey Shell, Paris
 Carol Smith, Knoxville
 Rick Spencer, Louisville
 Baretta Stewart, Memphis
 Andy Swanson, Franklin
 Ona Tierney-Cooper, Germantown
 Erin Worsham, Nashville

Partners 2001-02 Class Graduates in Style

On April 20th, twenty-four Partners in Policymaking participants from the 2001-02 class completed their leadership training and graduated in a ceremony at the Doubletree Hotel. Friends and family members accompanied graduating Partners, and joined them in celebrating the work accomplished during the last eight months.

Leaving the class behind was a bittersweet event. Although ready to get back to regular routines and the demands of family, jobs, and other commitments, there was sadness in saying goodbye to new friends and peers in the mission for disability rights and awareness, and realizing how much they would miss their monthly trips to Nashville.

Presentations by 1995-96 Partners grad Ken Tedford and former Texas Partners director Jopie Smith gave the class insights into what the future holds for those who have completed the Partners process, and what the program expects of its graduates. The weekend also afforded Partners an opportunity to get to know each other in a different light and on a more personal level through a

Friday night talent show, and a two-part photography workshop by *Kindred* photographer Simon Fulford. Some of the results of that session are on display throughout this article. ■

If you are interested in applying for the Partners 2003-04 class and eventually attending your own Partners Reunion, please contact Ned Solomon at:

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Council executive director Wanda Willis and Partners director Ned Solomon present Erin Worsham with her 2001-02 Partners graduation certificate.

Tennessee Disability

TENNESSEE
DISABILITY
INFORMATION
AND REFERRAL
OFFICE



10

So many places
to go for help.

One road to
take you there.



Life with a disability has
enough challenges. Figuring
out where to go for help
shouldn't be one of them.

Now, finding the resources you
need is fast and simple, with
familypathfinder.org. A few
clicks around this free website
let you explore Tennessee's
many organizations offering
essential services, information
and networking opportunities.

Visit www.familypathfinder.org,
or call (800) 640-INFO (4636).

familypathfinder.org

An Internet community for individuals
and families seeking disability resources
800-640-INFO (4636)

Offering 'Reliable Information
About Services Close to Home':
A Talk with Carole Moore-Slater,
Coordinator, Tennessee Disability
Information and Referral Office

**In a nutshell, please tell our
readers what the Tennessee
Disability Information and
Referral Office does?**

We know from listening to individuals
with disabilities and their families that
getting reliable information about
specific services offered close to their
homes is one of their greatest needs.
Our job is to connect callers with com-
munity programs that offer services
that might be able to assist with their
particular need. The most requested
services are related to housing, financial
assistance, Social Security disability
eligibility, and employment.

**How many calls are required to
identify a possible resource for
an individual?**

It varies. Information about particular
issues related to the Americans with
Disability Act (ADA), Social Security,
TennCare, Individuals with Disabilities
Education Act (IDEA), or general com-
munity resource information can usually
be answered in one telephone call,
sometimes followed up with a letter or
e-mail message. More complicated
situations require additional calls—for
example, individuals needing immediate
in-home care assistance, or immediate
day care for a medically fragile child, or
unusual situations like transporting a

child from a group home in California
when the family has minimal funds and
does not speak English.

**As you seek to help callers,
do you find that there are
important resources they
need that are lacking?**

With the current funding crisis in
Tennessee, many programs either have
long, very long, waiting lists, or do
not have the funding sources to accept
individuals, especially adults, into their
programs. Not much has changed in
Tennessee since I started five years ago.
In fact, in every quarterly report to the
Council on Developmental Disabilities,
housing, employment, Social Security
Disability, and financial assistance
were the top four categories of
services needed.

**What is the role of your office
in the community?**

I believe it's extremely important to
network with other agencies in the
community! We attend community
planning meetings and conferences
whenever possible to keep informed
about any service or funding changes
in Tennessee. I meet regularly with the
Middle Tennessee Alliance of I&R
Providers, established in 2000, to
discuss issues related to community
database sharing and the implementa-
tion of the National 211 Initiative to
link people with community resources.
The National 211 Collaborative was
formed in 1997 to help information
and referral services across the United

By Carole Moore-Slater

Information & Referral Office

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States to adopt this easy-to-remember number. Involvement with this group has been an interesting process and the Alliance is moving ahead with plans to share community information on a consolidated database to be accessed on the Internet.

Our program is expanding, and I'm excited about our new community outreach program for Spanish-speaking individuals seeking disability information. Solange Bishop, a bilingual information specialist with experience in the mental health field, assists with the rising number of I&R calls and assists Spanish-speaking individuals. Currently she is identifying Hispanic resources in various communities across the state that will ultimately be accessible on the Disability Information & Referral database through Family Pathfinder (www.familypathfinder.org).

How can people find the information you collect?

The *2001/2002 Tennessee Disability Services and Supports Directory* is available in three volumes, East, Middle and West Regions. Persons who want to order a printed directory can contact our office at 800-640-INFO (4636) or complete an order form online at www.vanderbilt.edu/kennedy/tdirs.html.

The Directory is also searchable on the Internet at **www.familypathfinder.org**. The Tennessee Family Pathfinder is an Internet community website for individuals and families seeking

disability resources. Both Tennessee and national resources are included.

In summary, there are several ways to access community information including the directory, online searchable database, by email and/or by calling the office directly.

How long have you been with the Tennessee Disability Information & Referral Office?

I've been working with this office since the program started five years ago. This office is located at the John F. Kennedy Center at Vanderbilt University, which is an ideal place to work. It has been the perfect job for me. I've spent more than thirty years working in the disability field. I've been a social worker in a hospital, a family support coordinator with a nonprofit organization, and a special education preschool teacher. Solange is knowledgeable about community resources from her former experiences with mental health agencies and has lived in Nashville most of her life.

We'd be happy to have you call.

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Solange Bishop
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**Tantos lugares
donde obtener
ayuda.**

**Un solo camino
a seguir.**



La vida con una discapacidad es difícil en sí. Averiguar dónde obtener ayuda no debe hacerla aún más.

Ahora es rápido y sencillo encontrar los recursos que necesita, gracias a familypathfinder.org. Con unos clics en este sitio web gratuito puede explorar las numerosas organizaciones de Tennessee que ofrecen servicios esenciales, información y oportunidades de relacionarse.

Visite www.familypathfinder.org o
llame al (800) 640-INFO (4636).

familypathfinder.org

Una comunidad en Internet
para personas y familias que buscan
recursos relacionados con discapacidades
800-640-INFO (4636)



In the Event of an Emergency

By Ned Andrew Solomon



In the days immediately following the September 11th aerial assault on the World Trade Center, the Pentagon, and the entire American way of life, citizens across the country got a wake-up call: as a society we were not adequately prepared for a disaster of this magnitude. And as evidenced by too many heartbreaking stories, perhaps the least prepared, and least prepared for, are our nation's citizens with disabilities.

Even more commonplace disasters, like fires or floods, render our homes and workplaces vulnerable, and put its inhabitants at great risk of losing lives or sustaining serious injuries. A recent Harris Interactive Survey reported by the National Organization on Disability reveals some startling statistics:

- 58% of people with disabilities say they do not know whom to contact about emergency plans for their community in the event of a terrorist attack or other crisis
- 61% say they have not made plans to quickly and safely evacuate their home
- Among those who are employed full or part time, 50% say no plans have been made to safely evacuate their workplace

Clearly, something substantial needs to be done. Fortunately, many resources have surfaced in recent months, including publications and numerous websites (referenced below) that specifically address the issue of better preparing individuals with disabilities and communities in the event of an emergency. In actuality, one of the best and most complete resources has been available since 1984, when the Los Angeles Chapter of the American Red Cross published a booklet entitled *Disaster Preparedness for the Disabled and Elderly*.

The current version of this exceptional guide, *Disaster Preparedness for People with Disabilities*,

with updated information, is readily available from your local American Red Cross chapter. Sections include understanding disasters (e.g., the difference between a “watch” and a “warning”), knowing what an environment may look like after a disaster, and how a disaster may affect an individual's independence.

Most important, the booklet emphasizes the importance of establishing a personal support network in the home, school, workplace, or any other location where one might spend a significant amount of time, so that other people in a person's life are ready to assist in an emergency situation. It contains a personal assessment form for recording building exits and ramp access and for listing what the individual will be able to do independently, and what assistance may be required before, during, and after a disaster. The form details any personal care equipment, adaptive feeding devices, electricity-dependent equipment, mobility aids, and vital medication or physician information that may be necessary to ensure the person's well-being. In addition, there is useful information regarding what items should go into a disaster supply kit, including food and supplies necessary to sustain the life of a service animal.

The website for the Federal Emergency Management Agency (www.fema.gov) has several extremely instructive articles about emergency preparedness for people with disabilities. Here are a few of the Agency's suggestions when trying to assist individuals with specific kinds of disabilities:

- Some people who are blind or visually impaired, especially older people, may be extremely reluctant to leave familiar surroundings when the request for evacuation comes from a stranger.
- People with impaired mobility are often concerned about being dropped when lifted

Web site Resources:

<http://www.redcross.org/services/disaster/beprepared/disability.html>
Disaster Preparedness for People with Disabilities

<http://www.jan.wvu.edu/media/emergency.html>
Emergency Procedures for Employees with Disabilities

<http://www.access-board.gov>
The Access Board—a federal agency committed to accessible design
Available resources on emergency planning

<http://www.epva.org>
Eastern Paralyzed Veterans Association (EPVA). Emergency preparedness information is found in the Government Relations Section.

<http://fema.gov>
Federal Emergency Management Agency (FEMA)
Emergency Procedures Manual for Office Employees with Disabilities
Now Available from FEMA in Variety of Formats

ADA Applies to Restoration of Damaged Facilities
<http://www.fema.gov/r-n-r/pa/papd/5.htm>

Disaster Preparedness for People With Disabilities
<http://www.fema.gov/library/disprepf.htm>

Fire Safety for People with Disabilities
http://www.usfa.fema.gov/fsrd/dis3_list.htm

Emergency Procedures for Employees with Disabilities in Office Occupancies
http://www.usfa.fema.gov/fsrd/dis_a64.htm

Preparing for Emergencies: Checklist for People with Mobility Problems
http://www.usfa.fema.gov/fsrd/dis_a66.htm

Fire Stops With You: Removing the Barriers: A Fire Safety Factsheet for People with Disabilities and their Caregivers
<http://www.usfa.fema.gov/safety/fswy22.htm>

<http://www.nsc.org>
National Safety Council

<http://www.nfpa.org>
National Fire Protection Association

Video:

United Cerebral Palsy of Middle Tennessee produces a series of videotapes of broadcasted shows, *Journeys: Redefining Ability*, which present topical disability issues. Videotape #6 has an informative segment on emergency preparation for people with disabilities. For information about when the program airs, or how to get a copy of the tape, please contact UCP at 615-242-4091, or visit their website at www.ucpnashville.org.



or carried. Find out the proper way to transfer or move someone in a wheelchair and what exit routes from buildings are best.

- People who are deaf or hard of hearing may not receive early disaster warnings and emergency instructions. Be their source of emergency information as it comes over the radio or television.
- Some people with mental retardation may be unable to understand the emergency and could become disoriented or confused about the appropriate way to respond.
- People with epilepsy, Parkinson's disease, and other conditions often have very individualized medication regimes that cannot be interrupted without serious consequences. Some may not be able to communicate this information in an emergency.

Furthermore, FEMA recommends working with neighbors or office mates who have disabilities to prepare an emergency response plan, and identify how you will contact each other and what actions will be taken.

However, whenever possible, people with disabilities should take responsibility for their own lives, and not wait for others to devise a

plan. In this regard, the United States Fire Administration strongly recommends that the following steps be taken:

- Plan your escape around your capabilities.
- Know at least two exits from every room.
- Ask your local emergency providers to keep your special needs information on file.
- Do not isolate yourself—speak up. People with disabilities are often excluded from the development and practicing of escape plans—resulting in safety needs remaining unfulfilled.

If we learned anything from September 11th, it is that a disaster can come at any time, hit any place, and take almost any form. The more prepared you are, and the more prepared the people are around you, the better your chances of survival, and of significantly minimizing injury. Start devising your personal safety plan today. ■

Ned Andrew
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of the Partners
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Leadership Institute
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Council on
Developmental
Disabilities.

Three

Three clients of the Tennessee Rehabilitation Center (TRC) recently shared with *Breaking Ground* their reflections on their traumatic brain injuries. The TRC, managed by the Tennessee Department of Human Services in Smyrna, is the State's only residential vocational rehabilitation training facility. It offers vocational evaluation, independent living skills training, and job development and placement. The telephone number is (615) 459-6811.

By Ashley Clark

My brain was damaged as a result of a car wreck. That accident changed my life forever.

Brain damage is one of life's little inconvenient occurrences. The choice is to fight it or accept it.

At first, I fought it. "This couldn't have happened to me!" I thought. "I did everything right in my life."

The easier way is to accept it. That was a big problem for me, but I had no other choice, really.

Part of my acceptance was the journey to TRC.

This was one of the best moves I could have made.

Here at TRC I can focus on the next steps I want to take in my life, not on what happened to me. I have learned not to dwell on my past but on my future. The staff has taught me that there's more to living than my injury.

With the help of my therapists, I found a volunteer job at a pet adoption agency, Love At First Sight. My responsibility was to be responsible for the care of baby animals. To look after something other than myself gave me a great, soothing feeling. These small creatures led me to have a brighter outlook on life. They showed me that if I had enough knowledge and concern to care for them, then I could do the same for myself.

They showed me that just because I have a slight difficulty, it doesn't mean I'm useless.

My accident and drastic situation didn't mean the world came to an end. It just changed. I'm special, and I still matter. ■

By Mike Pinson

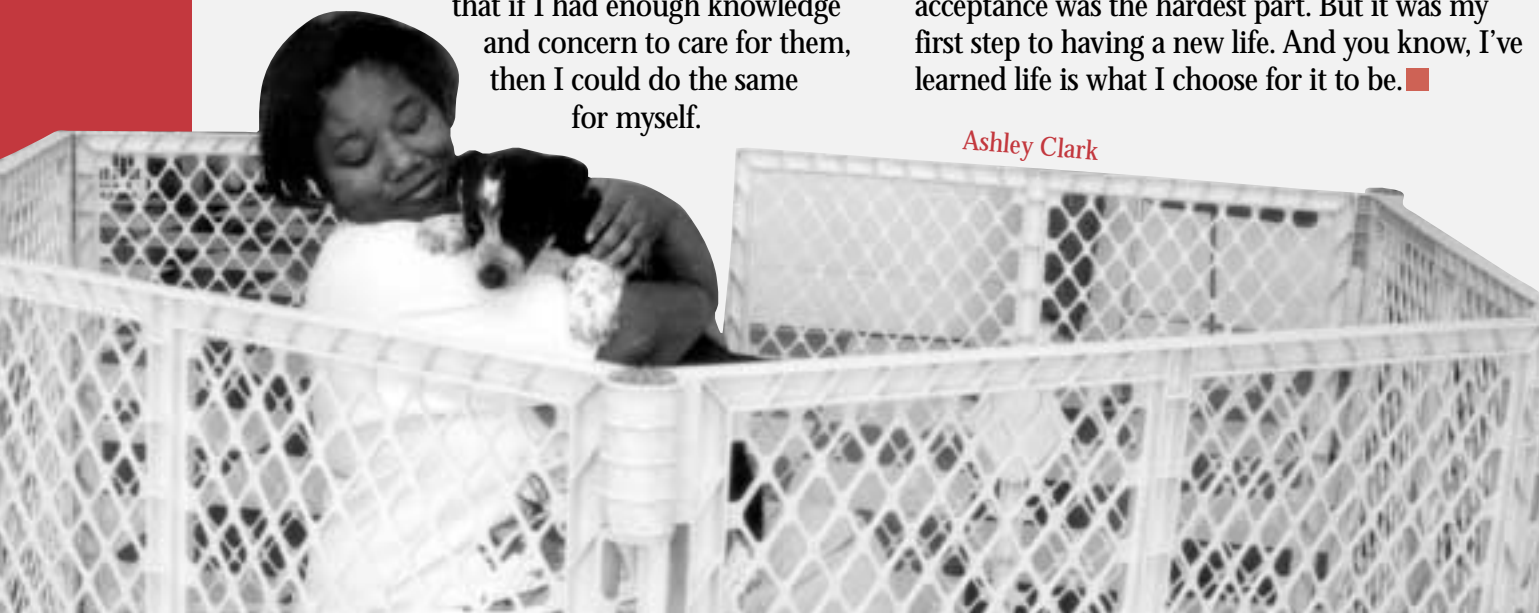
I have been a head-injured survivor for 16 years now. I was a college athlete when I sustained my injury. One moment I stood 6'3" tall and weighed 285 pounds. Then, in the blink of an eye, I was in a hospital, waking from a coma, and unable to walk. The doctors told me that I had had three golf-ball size portions of my brain removed.

The thought of being handicapped scared me. All during my teen years I had played football like nothing would ever happen. I had built my life around who I was out on that field, a star athlete. How would I get by without ever playing football? How could I make myself learn to walk again?

Scary? Yes, I'd have to say it was. But beyond my control, my new lifestyle began.

After an initial resistance, I finally accepted that I am an individual with a head injury. That acceptance was the hardest part. But it was my first step to having a new life. And you know, I've learned life is what I choose for it to be. ■

Ashley Clark



Confusion

By Elizabeth Anne McSwiney

Who is the strange man
In my room?
I remember Mark.
I remember Hubbard.
But who's this guy,
And where's Ollie?
I mean,
He's my fiance
And he should be here.
I see a ring
On this gentleman's left hand
And it looks like something
I would choose.
Now I remember—
It's Jerry!
Then I asked him
If we happened to be married.
He said yes,
Then left the room,
And cried.



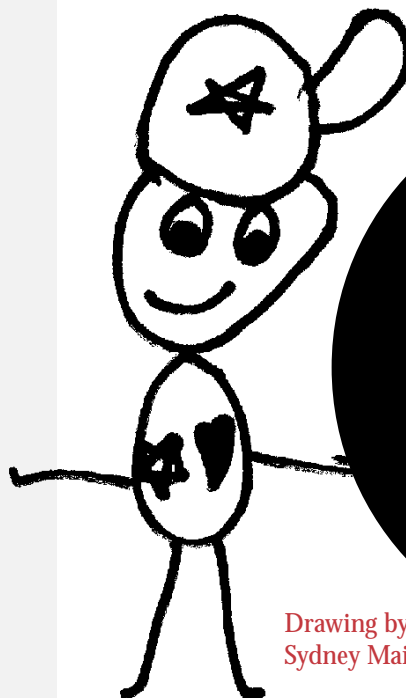
Elizabeth Anne McSwiney

Mr. Kellogg Takes the Helm

The Office of Health Services is pleased to announce the hiring of a new Deputy Commissioner for the Division of Mental Retardation Services (DMRS). Mr. Richard Kellogg began work on May 1.

Mr. Kellogg is the former Commissioner of the Department of Mental Health, Mental Retardation and Substance Abuse Services in the State of Virginia. In announcing the appointment, a spokesperson for DMRS said, "He is a strong leader with a firm commitment to human rights, consumer and family participation, and working together to achieve positive outcomes in the lives of persons with mental retardation. Mr. Kellogg was highly recommended by families, advocates, and professionals in Virginia and was the clear choice of the various family groups he interviewed with in Tennessee."

Sandra Sturgis, Interim Deputy Commissioner, will remain as the Director of Operations for the Division of Mental Retardation Services. She will serve as the Assistant Deputy Commissioner in charge of day-to-day operations and will help ensure continuity as DMRS moves forward with changes in its system. ■



**Summer Arts
issue coming in
August**

**See page 19
for details**

Drawing by
Sydney Maitland.

Launching the Tennessee Voter Project

By Andrea Cooper

16

Political participation includes a wide variety of components, but crucial to it are the activities of voting and participating in the voting process. Historically, people with disabilities have not registered to vote nor voted at the same rates as people without disabilities. There are myriad reasons for this disparity. Just a few include: lack of transportation to the polls, inaccessible polling places, inaccessible voting machines and forms, rules that prevent people from having the supports they need during voting, and attitudinal barriers of people administering the voting process.

On April 23, 2002, the Tennessee Council on Developmental Disabilities convened an organizational meeting toward a statewide consortium to increase voter participation of Tennesseans with disabilities. The Council believes that the partnership of a broad range of individuals and organizations is necessary in order to increase the number of Tennesseans with disabilities who vote.

Many groups have been interested in voter participation issues for some time. The Council, along with the Tennessee Disability Coalition, Tennessee Protection and Advocacy, Inc., The Arc of Tennessee, and United Cerebral Palsy of Middle Tennessee, among many others, are committed to making the disability vote felt in future elections.

The Council will use the consulting services of Mr. Jim Dickson, Vice President for Governmental Affairs of the American Association of People with Disabilities and head of their Disability Vote Project. Mr. Dickson will work with the consortium to suggest tools and methods that have worked in other parts of the country.

The mission. At the meeting, the Council outlined the mission of the Voter Consortium: to form the Tennessee Voter Project (TVP), a grassroots group of people who will address the following areas:

- 1) Voter education.
- 2) Voter registration.
- 3) Accessibility to all aspects of the voting process. For example, polls, machines, forms, transportation, personal assistance at the polling site, etc.
- 4) Voting. For example, get out the vote (GOTV) activities and motor voter registration (MVR).
- 5) Systems policy and systems change. For example, education and advocacy so that people with disabilities are seen as a permanent and important voting group; getting full compliance with the National Voter Registration Act in Tennessee, and getting media and other polling entities to recognize individuals with disabilities as part of their polling activity.

Role of the Council. The Council will have the following responsibilities to the Tennessee Voter Project.

- 1) Facilitate and coordinate activities of the project.
- 2) Serve as host at monthly meetings of the project.
- 3) Coordinate the evaluation of project outcomes.
- 4) Facilitate communication between the project principals.

Role of Tennessee Voter Project Members. The Tennessee Voter Project, as an entity, will have the following responsibilities. Individual member groups will take on specific activities as the TVP members agree those activities best fit the specific abilities of that member organization.

- 1) Based on expert consultant input, identify the key elements of a Tennessee voter initiative.
- 2) Identify resources throughout the state to assist in a statewide voter initiative.

- 3) Identify priorities for GOTV campaign.
- 4) Develop the statewide strategic plan based on the missions.
- 5) Coordinate and facilitate the involvement of all segments of the disability community.
- 6) Coordinate and facilitate involvement of people and agencies that support and serve people with disabilities in any manner. For example, occupational therapists, physical therapists, para-transit, Tennessee Network of Community Organizations, and Association of Sign Language Interpreters.

Response to the call for the organizational meeting was gratifying. Representatives from nearly twenty organizations from across the State were in attendance.

Jim Dickson congratulated Tennessee for being one of a handful of states to organize a voter movement. He cited the importance of voter registration, education, and access to polling places but said that the most important activity is to get out the vote.

Mr. Dickson reported that people with disabilities is the only significant group which is not identified in public opinion polling information or exit polls. The only newspaper beginning to make this identification is the *St. Louis Post Dispatch*. He suggested that this would be another opportunity for activity in Tennessee.

Carol Westlake, executive director of the Tennessee Disability Coalition, described some of the work the Coalition has done over the past two years with their VOTE! Campaign. Finding the voters who identify themselves as voters with a disability and consider disability issues when they vote has been an initial activity. To date, they have a database of 5,000 voters and their goal is to reach 50,000.

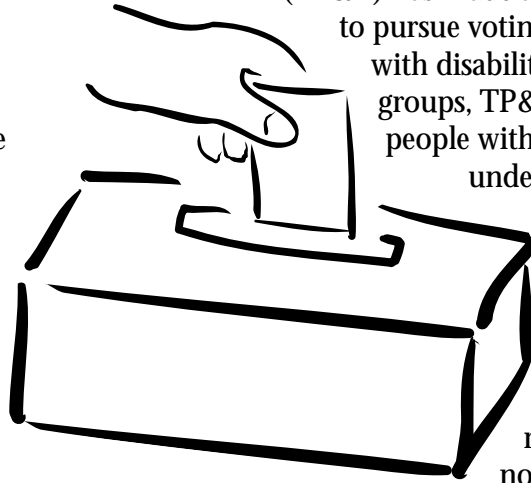
The VOTE! Campaign approached Tennessee legislators who were running campaigns during the last election cycle and convinced a few of them to have their pollsters add one or two questions regarding disability issues. The candidates who did this discovered high positives as

a result, especially on an issue like home- and community-based services. A key role that the Coalition will take with the Tennessee Voter Project will be getting people registered to vote.

Shirley Shea, executive director, told the group that Tennessee Protection & Advocacy (TP&A) has made a four-year commitment

to pursue voting initiatives for people with disabilities. Through focus groups, TP&A has found that people with disabilities do not understand that they have the right to vote just like any other citizen.

TP&A intends to develop a curriculum to let people know that they do have the right to vote. It does not matter whether they



live in a nursing home, congregate housing, with relatives or on their own, or what type of disability they have. Anyone who is over age eighteen and is a resident of Tennessee is eligible to vote. TP&A will train others to work in communities across Tennessee. The message to families and individuals with disabilities will be: Vote! And people will learn the basics about registering to vote and voting.

Ms. Shea explained that TP&A will be looking for lots of collaboration to accomplish this important work. She also said that they will strive to go beyond educating people with disabilities and work to educate poll workers and the general public about the right of people with disabilities to vote.

This is an important election year in Tennessee. The Council urges readers to take part in this critical work. ■

For further information about the Tennessee Voter Project, please contact the Council on Developmental Disabilities at Phone: (615) 532-6615 or E-mail: tnddc@state.tn.us

Andrea Cooper
is a member of
the Tennessee
Developmental
Disabilities Council
and Chair of the
Voter Consortium.

Voting and Disability Policies— There's a Connection

By Andrea Cooper

If Americans with disabilities voted at the same rate as people without disabilities, at least five million additional votes would have been cast on November 7, 2000. A major reason for the failure of most Americans with disabilities to vote is they are not registered to vote.

At least nine million Americans with disabilities are not registered to vote. In 1993 the National Voter Registration Act (NVRA or Motor Voter) was signed into law. While NVRA makes voter registration available at motor vehicle and public assistance agencies, many persons with disabilities are not being reached. For this reason, Section 7a of the NVRA says that "each state shall designate as voter registration agencies...all offices in the state that provide state-funded programs primarily engaged in providing services to persons with disabilities." Private nonprofit organizations and state agencies are covered by the law. Some agencies, but by no means all, that are covered under this law include: Vocational Rehabilitation; Special Education; Commissions for the Deaf and the Blind; Para-Transit Providers; Independent Living Centers; Disability-Specific Service Providers such as ARCs, Multiple Sclerosis Society, Epilepsy Foundation, Muscular

Dystrophy Associations, and so forth. If the primary activity of an organization is to provide services to persons with disabilities, and if it receives state funding to provide these services, the organization must be designated as a voter registration agency.

Register anywhere. All public and private agencies serving people with disabilities are required to offer voter registration to their consumers when these last sign up as clients, are recertified for benefits or services, or change their address. If an agency's services

are not provided in agency offices, the person who provides itinerant services must also offer voter registration services. If the individual declines to register to vote, the agency must obtain the individual's signature on a declination form and keep that form on file for 22 months.

Most disability agencies are in violation of the NVRA. A 1998 National Organization on Disability/Harris poll reports that only 25% of people with disabilities have been asked by a service provider to register to vote.

Human service and health organizations can help empower their consumers by systematically offering voter registration during the application, intake, or orientation process, and by registering all of their employees to vote. Many will vote. Studies show that 70% of the people whom volunteer canvassers register in welfare and food stamps offices vote in presidential elections.

A numbers game. While many of the goals sought by disability advocates and service providers are often achieved through the participation of small groups of consumers, voting requires a radically different mindset. Voting requires participation by many. Voting is a way to ensure that elected officials are responsive to voters' concerns on all types of issues. Therefore, it is important to always think in terms of getting every voter with disabilities to the polls when it comes to getting out the vote.

Getting out the vote applies at least as much to primaries as it does to general elections. It's most often in the primaries that candidates' positions on the issues are formed and hardened. ■

If you are interested in getting involved with the Tennessee Voter Project, please contact The Council on Developmental Disabilities
Phone: (615) 532-6615
E-mail: tnddc@state.tn.us

*Andrea Cooper
is a member of
the Tennessee
Developmental
Disabilities Council
and Chair of the
Voter Consortium.*

Inviting you to contribute to a SPECIAL ISSUE of *Breaking Ground* devoted to the arts

Coming in August 2002

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Do you write short stories or poetry? Do you paint, draw, or take pictures? Then we'd like to see your work for possible publication! The editor will consider

- fiction up to 1,000 words and poems, either traditionalist or modern
- photos, drawings, and cartoons, which can include people and be about humorous or serious subjects. This material must reproduce well in black-and-white.

Work with disability themes is preferred, and contributions by persons with disabilities are especially sought.

We'll give contributors a prominent by-line, a biographical note, and copies of the issue. Please address your submissions to Editor, *Breaking Ground*
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Peabody Box 40
230 Appleton Place
Nashville, Tennessee 37203-5701

Questions? Just call (615) 322-8473
or 1-800-288-0403
TTY (615) 343-3330 or 1-800-288-3311
or e-mail: Jim.Summerville@Vanderbilt.edu

Submit by June 15

Remembering Beth Sievers

A former member of the Tennessee Council on Developmental Disabilities, Beth Sievers died on February 3 in her home at Cookeville. She was born on March 9, 1958, in Ames, Iowa, to Joyce Arnold Sievers and the late Elwin Sievers.

Besides her service on the Council, Ms. Sievers was past president of People First of Tennessee and a member of Cookeville First United Methodist Church. She had been a devoted employee of O'Charley's Restaurant for the past eight years.

Teresa Meadows, operations manager for Pacesetters in Cookeville recalls, "Beth's outlook on life was uplifting and encouraging. She is a wonderful model of what we try to achieve for the individuals supported by Pacesetters. I had worked at

Pacesetters for a couple of weeks before I realized that Beth was supported by this agency. She was so outgoing, involved, and helpful to me the first few days I worked at Pacesetters, I thought she was a staff person."



Beth Sievers

"Beth was a pleasure to be around," says Tim Watson, owner/manager of O'Charleys in Cookeville. "At work, she was quick to remind us when we needed to do something. It was obvious how much Beth cared

about the success of everything she associated herself with."

A friend of Beth's, Norma Inman says, "Few of us ever reach our potential, but I believe Beth did. Whatever her limitations, they were overcome by her CAN DO spirit and determination. She believed in herself, and she used her abilities to the glory of God." ■

Editor: Mr. Jim Summerville
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About the Council:

The Tennessee Council on Developmental Disabilities provides leadership to ensure independence, productivity, integration, and inclusion of individuals with disabilities in the community through promotion of systems change.

The editor will consider for publication original contributions, including news and feature stories, short fiction, poetry, artwork, and photographs but reserves the right to edit or decline publication. Brief letters to the editor are also welcome. Opinions expressed in any published matter are the author's and not necessarily those of the Tennessee Council on Developmental Disabilities or its staff.

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